

Meeting of the European Parliament  
Informal Carers Interest Group

*'COVID-19, Informal carers and the need for an EU Strategy on Care and Caring*

**Virtual meeting of the Informal Carers Interest Group  
28 September 2021, 12.30 - 14.00**

**REPORT**

**Meeting Agenda:**

*12.30 -12.40 Welcome and aims of the meeting*

- Luke Ming Flanagan MEP
- Marisa Matias MEP

**The impact of COVID-19 on carers**

*12.40 –12.50 The impact of the COVID-19 pandemic on carers*

- Stecy Yghemonos, Director, Eurocarers

*12.50 -13.00 COVID-19 and carers: a personal story*

- Jane Johnstone

**Current EU developments: towards EU action on long term care**

*13.00 -13.10 Social Protection Committee report on Long Term Care*

- Ulrike Neufang, Vice-Chair, Social Protection Committee

*13.10 – 13.15 European Parliament report 'Old Continent Growing Older'*

- Tomas Zdechovsky MEP

**Panel response**

*13.15 -13.35 Speakers:*

- Dana Bachmann, DG EMPL, European Commission
- Alva Finn, Director, Treasurer, Social Platform
- Borja Arrue, Project and Policy Officer, AGE-Platform Europe

*13.35 -13.55 Audience debate*

*13.55 -14.00 Conclusions and close*

- Luke Ming Flanagan MEP
- Marisa Mattias MEP

## **REPORT**

### ***Welcome and aims of the meeting***

Luke Ming Flanagan MEP opened the meeting, welcomed participants and briefly stated the topic of the meeting, i.e., *EU level action on care and caring, within the context of the European Pillar of Social Rights and recent EP developments, such as the PPE initiative to advocate a European Care Strategy.*

He then briefly introduced the Informal Carers Interest Group, which aims to *critically monitor and analyse EU policy development for its impact on carers and to propose and advocate concrete action to improve the day-to-day situation for Europe's many carers, working in close partnership with relevant stakeholders.* The Group is currently supported by 26 MEPs and aims to meet twice a year, addressing current EU policy developments, relevant to informal care and carers. One of the focus points of the Group is to ensure the adoption and implementation of an EU Long-term Care Strategy which would explicitly address the issues and needs of informal carers.

Background to the meeting is the fact that the Interest Group, together with Eurocarers, has been working for several years now to advocate for an EU Carers Strategy. Its last meeting, held in February highlighted the increasing policy interest on long term care and carers. It underlined the consultation on the implementation of the European Pillar of Social Rights, its outcome and next steps, with a link to the Portuguese EU Presidency's specific plans. It also focused on the EPP initiative in the European Parliament on a European Care Strategy and explored possibilities for EU action to increase concrete policy attention for long term care/carers across the board.

In this light, it was felt it would be interesting to have a closer look at the impact of the COVID-19 pandemic on carers.

### ***Speakers***

Luke Ming Flanagan MEP then gave the floor to **Stecy Yghemonos (Director Eurocarers)** to present the findings of the Eurocarers study on the impact of the COVID-19 pandemic on carers.

Before doing so, he outlined some main facts about informal care provision and carers, stating that informal carers are largest providers of health and social care support. They make up about 10-20% of the total EU population, with women providing two-thirds of the care (mainly as daughters (in law) and spouses/partners).

The value of informal care is estimated between €320 and 368 billion across the EU. Research has found a strong correlation between caring and work-life/care balance, social exclusion and poverty as well as health and wellbeing.

Turning to the impact of the COVID-19 pandemic on carers, Stecy Yghemonos stated that a recent study - carried out by Eurocarers and INRCA - has found that social network and societal participation and quality of life were most affected (as indicated by 78.7% and 76.8% of carers). Other areas where the pandemic has made its presence felt were mental health and well-being (66.5%), access to care services for the person cared for (59.8%), and the health status of the person cared for (54%).

It was also found that, on average, at least 17 hours of extra care were provided per week and that the care provided was more intensive. Interestingly, the pandemic has had an impact on the number of carers: this increased by 11.9%.

The pandemic has also had an impact on care services as one-third of carers interviewed indicate that support has decreased. The most effective sources of support were family members (42.2%), pharmacists (40.1%), friends and neighbours (21.7%), general practitioners (20.8%) and lastly, public health services/professionals (17.9%).

The pandemic has brought a number of these issues to the fore, and the report therefore concludes by arguing for a better interface between formal and informal care and more support to civil society organisations. The potential of technology should be explored and exploited to support carers, even though more than 3 quarters of respondents (77.8%) have never used care-related technologies and only 27% of carers state that they would be interested in using them. Issues related to cross border informal care should also be addressed.

Steyc Yghemonos concluded by calling on policy makers to acknowledge and support carers across policies. A European Strategy to empower and support carers, as proposed by Eurocarers (add link - <https://eurocarers.org/publications/enabling-carers-to-care/>) would be a useful tool to ensure this acknowledgement and support. The Commission's announcement to put in place a European Care Strategy, made by Commission President von der Leyen in her recent State of the Union address, is therefore very welcome.

**Luke Ming Flanagan MEP** then invited **Jane Johnstone** to share her personal experience of being a carer during the pandemic. Jane Johnstone provided a powerful description of the challenges she encountered during the pandemic, as a carer for her two sons with profound and varied care needs.

Before the COVID-19 pandemic the family situation was already a highly challenging; but it grew much worse during the pandemic. The impact of day care centres and special schools closing meant a breach of regularity and social contact, which led to serious situations. Confinement caused anxiety and stress to Jane's sons as they were difficult to explain and maintain.

Support was on offer but only when the situation reached crisis point and was near breakdown. Carers were not included in PPE distribution in Ireland; the cost of – or instance - gloves increased from 5 Euro to 20 Euro per box making them unaffordable; yet they were basic to health and safety. Fortunately, Family Carers Ireland supplied them; without this support, spending on food and/or fuel would have to be cut.

Moreover, carers were not prioritised for vaccination in Ireland, despite strong advocacy efforts. But if Jane Johnstone would have contracted COVID, the situation would have spiralled downwards totally as she is vital to the daily lives of her boys. The structure, home and care of her sons would have arrived at a complete crisis requiring emergency intervention from the health service. However, despite this fact – which holds true for carers across the board - the health services did not recognise the crucial role of carers.

While the world is slowly emerging from COVID, this is not the case for Jane Johnstone and her family. The situation is still very difficult – it was difficult before COVID, but COVID made it far worse; the impact of the crisis is still strongly felt by the boys, e.g., lost skills previously learnt in school that need to be regained and additional health complications.

However, the boys (and many other people cared for) are good examples of resilient and endurance. Policymakers have a duty to include people like them.

Jane Johnstone welcomed the announcement of an EU Care Strategy and stated that for her, this should cherish carers and recognise them as absolutely vital to the health service, to communities and to society.

Carers want to live lives like everybody else. They want the right to sick pay, to annual leave and to the right to retire. Finally, Jane Johnstone underlined that carers should be relieved of the fear of what will happen to their loved ones when they fall away. Quality care should be available to everyone - and reliable.

**Marisa Matias MEP** then gave the floor to **Ulrike Neufang (Vice-Chair of the Social Protection Committee)** to share the main messages of the recent Social Protection Committee (SPC) report on long term care, with a particular focus on the report's statements on informal carers. The SPC is an advisory body to the EU Social and Employment Ministers (EPSCO), established by a formal Council Decision. Its members are senior level official representatives from the 27 Member States; the Committee meets at least once a month. The SPC's mandate covers all major social policy strands, i.e. social protection and social inclusion, pensions, health care, long-term care.

Since 2010, the SPC has addressed issues relating to long term care and has published various reports directly and indirectly addressing this topic. The Committee is also actively involved with the European Semester Process, and the development of indicators (within the SPC Indicator Sub-group).

Ulrike Neufang then turned to the recent SPC report on long term care, which consists of two parts: one presenting a set of key conclusions on 6 crucial dimensions of long term care – including a chapter on the long term care workforce and informal carers, and a second presenting 'country fiches', containing descriptions of the situation in Member States in relation to the main challenges, reform trends in long term care, as well as a set of key figures for each Member State.

The report's conclusions highlight that the demand for high-quality long term care is set to rise and reinforcing its provision can contribute to gender equality and social fairness. They also state that access, affordability, and quality are key challenges in relation to long term care; and that an adequate workforce is key to meeting the rising demand for high-quality services, but the current labour shortage may intensify further. Informal care has been essential in long term care provision, but this often comes with neglected costs and may not be viable in the future. Reforms of long term care systems, and the investment related to it, need to be pursued further and should build on the lessons learnt from the COVID-19 pandemic.

More specifically on formal/informal care, it is stated that meeting the rising demand for long term care can support job growth, but that Member States struggle to attract and retain care workers. Difficult working conditions and low salaries may contribute to staff shortages. Informal care often comes with significant costs for the carers. In parallel with efforts to reinforce formal care services, supporting informal carers is also important. Adequate and affordable formal long term care services, together with policies to improve working conditions in the sector and reconcile paid employment and caring responsibilities, could support gender equality.

The SPC therefore considers that there may be scope for further work at EU and Member State levels to address long-term care challenges. Further reforms need to be pursued by Member States to address structural weaknesses in long term care systems and to make them more resilient to future external shocks. It also considers that, despite the progress made in developing common EU indicators on long term care, important data gaps remain. Further consideration of how to shape long term care policies and systems is required and therefore the SPC intends to prepare a third joint long term care report.

The next speaker, **Tomas Zdechovsky MEP (by pre-recorded video)** highlighted the main conclusions of the recent European Parliament report 'Old Continent Growing Old', with an emphasis on what the report contains in relation to informal carers. He emphasised that, due to demographic ageing and several other demographic changes, both formal as well as informal care provision is under pressure. Therefore, Mr

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Zdechovsky MEP tabled several amendments to the report, which were adopted; the document now speaks about the important role of informal carers.

Most of the informal care is provided by informal carers that are often over the age of 65. This is an important fact that needs to be considered by the Commission and the Member States when they prepare legislation that may have a bearing on carers as well as on older and dependent people. Due to Mr Zdechovsky MEPs' amendments, the report now calls on the Commission for an EU Care Strategy and urges Member States to recognise the value of informal care. In conclusion, Mr Zdechovsky MEP expressed his full support to keep the pressure on the Commission so that policy attention for this important matter can be assured.

### *Panel*

**Marisa Matias MEP** briefly introduced the panellists and stated that they had been asked to prepare statements based on the following guiding questions – also shared in advance with participants.

Given the increasing realisation and recognition of the need to address long term care in general and informal care (demonstrated by the Social Pillar, the EPP initiative on long term care, the SPC report and the European Parliament report):

- How can this recognition be leveraged and harnessed to ensure an ambitious and coherent EU initiative/strategy on long term care, which takes appropriate account of informal carers?
- What could your organisation contribute towards the development and implementation of a specific EU initiative/strategy on long term care?

**Dana Bachmann (Head of Unit 'Modernisation of Social Protection Systems, DG Social Affairs, Employment and Inclusion, European Commission)** started by highlighting the timeliness of the meeting given the recent State of the Union address in which Commission President Ursula von der Leyen expressed a clear commitment to come forward with a European Care Strategy.

The Commission is and has already been looking at this topic from various angles, taking its multiple dimensions into account. The recent SPC report is a good example of robust analytical work; it provides a good snapshot of where the various national systems are in terms of access, affordability, quality, workforce, informal care and financing of LTC. Apart from the analytical work the Commission makes use of several other instruments to support reforms of long term care, such as the European Semester with its country specific recommendations, and the Social Open Method of Coordination, facilitating the exchange of best practices and developing indicators in these areas. Moreover, the European Social Fund finances several social innovation projects with a focus on long term care, and Horizon Europe and Digital Europe programmes also address this issue.

Dana Bachmann underlined that it is important to change the current negative narrative with respect to long term care as the main emphasis seems to be on its challenges and costs. However, long term care also brings opportunities, e.g., to grow an essential sector of economy, where social economy organisations and civil society organisations play a key role alongside public authorities, to create and foster quality jobs into the community, responding to local needs.

As regards the future European Care Strategy, preparatory work is ongoing. Through the European Pillar of Social Rights Action Plan the Commission already committed to two care related initiatives: one on LTC and one on the revision of the Barcelona targets for childcare. In the field of long-term care, the starting point relates to challenges identified through recent public consultations on ageing and on the Social Pillar Action Plan; these have yielded many suggestions and ideas for action on long term care, as

well as the analytical mapping of the joint SPC EC Long Term Care report. There was a large convergence between the challenges identified in this report and the feed-back received through the public consultations.

Clearly, there are challenges in terms of access and of the availability of services. Affordability is another aspect. Calls were made also for integration of long-term care into social protection systems and strengthening public coverage for long term care related costs, while a number of stakeholders also called for measures aimed at increasing cost-effectiveness and incentives for private based insurance. The formal care sector faces challenges, as issues like low pay and health and safety issues need to be addressed to make these jobs more attractive. Shortages of formal care workers are already coming to the fore and these may continue to increase.

Dana Bachmann echoed the messages of previous speakers regarding the key role of informal carers as they provide the largest share of care. Public interventions have the potential to support carers to a larger extent, while expanding quality and affordable formal long-term care would increase support for informal carers.

The fundamental principle should be that that informal care should be a choice; this choice should be accompanied by a range of social services, guaranteeing the best services for those cared for as well as for those providing care. Another dimension is the quality of services. This needs further thought as there are many dimensions of and approaches to the concept of quality.

There is much work to be done and the European Care Strategy should also build on already existing initiatives, while also carefully considering EU competencies in the field.

Dana Bachmann invited participants to maintain the dialogue with the Commission and to share thoughts views and suggestions.

**Alva Finn (Director, Platform of European Social NGOs)** welcomed the State of the Union address and the Commission's commitment to a Care Strategy. She stated that care work must be valued; recognition of its importance as such is not enough. She focused on 4 topics:

An inclusive, coordinated approach to care is required, that looks at the experiences and needs of everyone – both those receiving care and those giving care. A more coordinated approach to care, health care and social protection services is also needed, to ensure that they work alongside rather than against each other. In this spirit, an EU strategy on LTC would pair well with an EU strategy on social services. the Strategy should foster better working conditions for the care sector as this would help lift the pressure on informal carers. An EU Care Strategy care should also set guidelines and minimum standards on the quality, accessibility, affordability and availability of services that promote independence and social inclusion, as well as cover how these services are provided. Training, retention, skills, and quality working conditions like setting minimum wages all come into play.

To create better conditions, the current funding gap of the care sector needs to be addressed. The lack of funding is why there are so many informal carers to begin with. Moreover, to be successful the EU Care Strategy must be supported by sufficient social investment, given that the EU's recovery funds do not explicitly go towards the care sector.

It is mainly women that take on formal and informal care roles. It is time that this contribution to society is recognised and valued. There has been a huge impact on the income, pension, and quality of life for these caring women, and this needs to be addressed to avoid even bigger poverty gaps emerging for women.



There is a need for an inclusive approach to care: civil society, service providers (public, private and not for profit), social partners, and those who provide and receive care, should all be involved in the conversation from design to implementation and monitoring, so that policies truly benefit the people they are designed to help.

Alva Finn concluded by stating that the Social Platform is ready to work with the Commission and is well placed to do so as it represents the needs of all people – receiving and giving care – in their diversity.

**Borja Arrue (Project and Policy Officer, AGE-Platform Europe)** stated that care provision has been one of the most important topics for AGE-Platform Europe as care systems across the EU have been and cannot ensure access to care services for all older people who need care. A survey carried out in 2014 found that only 1 in 3 older people gets the care they need at home; another survey, published in 2019, found that in 50 % of the cases, older people have at least one care need that is not addressed.

A report on the human rights of older people during the COVID-19 pandemic has pointed out that situations of elder abuse are on the rise. In many cases, the abuse is inflicted by family carers, due to lack of support or training. When professional services not available, the risk of abuse increases.

Access to quality care is crucial for those who need care as well as for informal carers. Fortunately, the political interest in long term care is increasing because of pandemic; it is more of a priority now and a European Care Strategy can help to make sure that Member States do not forget about this topic.

Borja Arrue welcomed the intervention made by Dana Bachmann, which underlined and confirmed the interest of the Commission. Many pieces are on the table already – work carried out by the OECD and the SPC as well as other research; the evidence and the knowledge of the situation is there. The EU Care Strategy should bring all of this together and make a strong case for Member States to invest in long term care of into supporting informal carers.

The Strategy should be comprehensive and address the various elements of long term care, which makes it quite complex. Quality of services should be one of the core starting points, looking into what the goals of the various services are.

A new, fresh look is required when addressing long term care, with a stronger focus on the opportunities rather than on challenges and cost. New policies require new thinking and work has already been done on that front.

The SPC report on long term care can serve as a reference work for advocacy over the coming years; and advocacy should be about how services can support and boost empowerment, equality and participation, also for informal carers – ensuring that caring will be a personal choice.

### ***Conclusions and close***

**Luke Ming Flanagan MEP** stated the need for additional financing for the important area of care. Getting additional funding is about convincing policy makers to do so; these are political choices. Public support is an important factor in obtaining additional financing and this topic is one that affects us all – it either has in the past, does so now and will in the future.

We should look at what we are trying to achieve and where we currently spend our money – and maybe the focus needs to change. Carers should be recognised and valued, and this is not the case now. The

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Interest Group will continue to fly the carers flag and put pressure on the Commission to ensure the appropriate policy attention for this topic.

**Marisa Matias MEP** stated that the discussion seems to focus on financing and competence issues – and these should not be in the way of advancing a Strategy. It is not acceptable to ignore the 10% of the population that is providing informal care. MEPs have been advocating a proposed Care Strategy since 2011, when the discussion focused on Alzheimer's Disease.

Long term care is not just about older people – it concerns the life span, and it concerns large groups of people from all ages. It is difficult for carers to organise themselves or advocate as they are simply too busy caring.

While Marisa Matias welcomes the announcement of an EU Care Strategy, she stated that we need to add content to that as soon as possible. It is time to make the choices that matter and face the real priorities. Rather than talk about costs and competence we need to focus the discussion on investing in our lives and quality of life. It is much more expensive not to take care of the carers than ensure proper services and support.